

**Long Term Care Coalitions
Suggestions and Concerns
Public Meetings on 1115 Waiver**

During May and June 2002, community Long Term Coalitions around the state convened public meetings to begin the public dialogue about the Department's interest in expanding Vermont's current "1115 Waiver" to restructure our long term care Medicaid programs. The primary goal of this Waiver expansion is to remove the institutional bias toward nursing home placement and create more equal access for consumers to either home based care or nursing home care, depending on the consumer's assessed needs and a fully informed choice on the part of the consumer and his/her family. This goal would be accomplished by creating one long-term care budget, which would combine the Medicaid dollars for both nursing home expenditures and those attributed to the Home and Community-Based Waivers. Combining these funds would allow more flexibility in serving both elders and persons with disabilities. The Department has received a grant from the federal government to pursue such a Waiver.

The Department asked attendees at the meetings to describe services that might help individuals live in the settings they prefer. DA&D also sought input on how a service delivery system based on a combined budget might work. These meetings were a great success. The public participation included providers, consumers and other interested persons. Over 300 individuals attended the meetings around the state. Below are suggestions and concerns voiced at these meetings. The comments are organized by Long Term Care Coalitions. If you have additional concerns, comments or feedback please email them to Joan Haslett (joanh@dad.state.vt.us). The Department welcomes additional suggestions.

DEPARTMENT OF AGING AND DISABILITIES

1115 Waiver Discussions

Feedback, suggestions and concerns

Lamoille Valley Long Term Care Team

May 15th, 2002

Managing a Long-term Care System with a combined budget

- Give more flexibility to move services for clients between agencies
- Who decides what services are delivered? Build in flexibility. Let the consumer decide what services to purchase

Proposed services to include in system

- Fairness~how do you equalize benefits when one person has a \$1,000,000 home compared to someone who has a \$50,000 home?
- Paying for housing costs like taxes, fuel, etc., cost to maintain house
- More prevention, e.g. physical activity, physical therapy
- Fund alternative therapies and support groups
- Cover transportation to activities
- Cover hearing aids and dentures

Additional Support Needed for LTC System

- No comments

Eligibility

- Change eligibility requirements for long term care need. Don't wait for the individual to need nursing home level of care. What should the mix look like between the number of people who need nursing home level of care and those who needs services, but not at that level?
- Financial eligibility~ what about a sliding scale for Medicaid Services Long term care?
- Services for individuals with disabilities under the age of 60

Reimbursement For Services

- Cost of services – should be co-pays based on your income/capacity to contribute
- Pay spouse or family member to provide care

- Could Medicaid paid for housing such as the “HASS” (Housing and Supportive Services) services?
- Co-pay for individuals close to eligibility for Medicaid
- Sliding Scale – could allow us to support services for younger individuals without going broke

Concern

- Annual inflationary increase for nursing homes ~ will that effect budget neutrality?
- Joining the State’s current 1115 Waiver -- Do we want the risk of being connected to “PATH” and “Mental Health” in this type of Waiver? Can we function with a gentlemen’s agreement to each maintain budget neutrality?
- Pharmacy budget should not destroy long term care services
- Independent Living Assessments~simplify process

Northeast Kingdom Coalition
St. Johnsbury

May 17th, 2002

Managing a Long Term Care System with a combined budget

- No comments

Proposed Services to include in the system

- Need 24 hour care in the community
- Need to design services for persons with dementia
- NY waiver provides housing, transportation, etc.VT does not
- Nursing Home pays for housing, transportation, recreation, current DA&D waiver do not
- Physical therapy-Medicaid current imposing a one-year lifetime cap need may include ongoing PT.
- Pay for strong living programs

Additional Support needed for LTC System

- Develop caregiver program and agency to run it ~need state support to do this
- Caregivers need support, i.e. benefits
- If we increase slots~how do we provide staffing to cover the care needs.
- Small adult family care homes are needed. Licensing to take more than 2, need regulation to ensure safety.

- Use nursing home for non-dementia individuals during the day to get social interaction

Eligibility

- Gap in services for individuals under 60
- Lower eligibility gear programs

Reimbursement of services

- No comments

Concerns

- Expanding aging population~25 years from now will really impact the system
- Need bricks and mortar dollars to expand programs
- We need Single Payer System. The healthcare system should not discriminate

Addison County Long Term Care Coalition

May 30, 2002

Managing a Long Term Care System with a combined budget

- No comments

Proposed services to include in system

- No comments

Additional Support needed for LTC Systems

- Expand hours in waiver program so supervision can be provided

Eligibility

- Create separate Waiver for people with dementia

Reimbursement for Services

- Person who is “bed bound” presents certain challenges. It is problem paying for discrete tasks
- Need a sliding fee scale for Medicaid services

Concerns

- State needs to look at the imbalance in waiver utilization thru out the state

Northeast Kingdom Coalition

May 31,

2002

Newport

Managing a Long Term Care system with a combined budget

- No comments

Proposed services to include in System

- Increased number of Adult Day sites
- More use of nursing home facilities for Adult Day, look at barriers to making this possible
- Transportation missing to Adult Day. Need assisted transportation for some individuals
- Nighttime care at home is needed, particularly for persons with dementia

Additional Support needed for LTC Systems

- No comments

Eligibility

- People under age 65-separate out disability determination issues

Reimbursement for Services

- Problems with Consumer Directed/Surrogate Directed (CD/SD) payments before POC (plan of care) approval is in place. Should have a system that allows for presumptive eligibility so services can start

Concerns

- Have meeting separately with nursing homes to discuss 1115 waiver idea

Washington County Long Term Care Coalition June 3rd, 2002**Managing a Long-term care system with a combined budget**

- Global budgeting does not work

Proposed Services to include in System

- Change empty nursing home beds to assisted living
- Fund transportation to social events
- Need someone in the home at night, finding someone you could trust isn't easy
- Shared housing is possible
- Expand housing & supportive services
- Caregiver respite~needs to cover short term—one or two weeks
- Fund programs to promote good nutrition, healthy weight and exercise
- Provide for the end of life care in a waiver

Additional Support needed for LTC System

- Lack of nurses and enough other staff to do the work
- Use the small village concept~help one another
- The state needs to pay attentions to staffing issues
- Want to retain nursing homes but change them so they meet the needs of the consumer

Eligibility

- No comments

Reimbursement for Services

- Need rules & regulations changed so agencies are paid by allowable cost
- Create policies to allow self payers to buy in
- Add other things to the waiver to help, for example paying the 1st months rent for someone leaving the nursing home who has lost his/her community housing
- Match flex funds with Medicaid to expand money available

Concerns

- Need both nursing home and Home & Community Based Services in the system. Find ways to help nursing home diversity before they have to close
- If new nursing homes are created, they should not be a single purpose type building
- One on one care is difficult
- Client assessments should build in more social supports not be so focused on the tasks needed
- Lifeline too expensive
- People in nursing homes should be there
- There are people are in nursing homes that could be somewhere else
- Don't wait to plan for the baby boomers – there will be an increased need in caregiver support due to the number of people needed care may increase sooner due to long term disabilities
- Need to proceed cautiously
- Need to consider current funding and plan for incremental increases. Ease into a new Waiver
- Burden of risk is large; who will take it on?
- Balance is too far on the institutional side

- Look at deinstitutionalization efforts in the past to see what was in place what worked

Champlain Long Term Care Coalition

June 12, 2002

Managing a Long-term care system with a combined budget

- Who will decide what services are needed? When it is decided would not like to do battle with a far away entity. would like to see local case managers, and/or consumers make decisions. Would like flexibility. Should make decisions with a cap on expenditures
- Let individuals manage their care independently, thru their attorney or accountant rather than the State's financial contractor. More money will then be available for care

Proposed services to include in System

- Adult Foster Care options
- Transitional services as part of the waiver~what would be covered amending the current Medicaid waiver? First month's rent, deposit, purchase of necessary furnishings?
- How do we do quality assurance and attend to customer satisfaction?

Additional support needed for LTC System

- Lack of caregivers for individuals
- Chronic problem of staffing in the current Waiver. Hours determined for plans of care are not fulfilled. Discharged from nursing home~home may be a 30 day wait because caregivers are not available to provide level of service. What is the quality of care when only received 12 hours when 20 are authorized?
- Use money to buy care in private homes, because residential care homes will not take waiver clients
- Need to get to the caregiver (spouse) in the community better educate individuals in need about what is available

Eligibility

- Financial eligibility~ eligibility for spouse when a there is a disparity in income between the spouses
- Need to demystify the estate recovery~so elders will access services
- Presumptive eligibility for services should be made possible to streamline the process

- Use the housing approach to eligibility, i.e. look at total household income and percent they are paying for housing.
- Long Term Care rules remove ability to enhance the income of community space. Should make sure there is integration between development of long term care rules and policies that support long-term care in the community

Reimbursement for Services

- Transportation needs a sliding scale
- Increase ACCS (Assistive Community Care Services) rate to cover actual costs. Use Waiver to draw down enhanced federal match to bring it up to cost
- Provide compensation for family care givers

Concerns

- Need to look at a breakdown of expenses, between Medicare, Medicaid, Older Americans & LTC insurance
- Where will we be in 10 years when greater numbers of nursing home beds are needed?
- Unfair -- some people spend money like water and get services, others save and are overwhelmed with needs and have to spend their money. It's demoralizing to people to become destitute in order to get services
- Pharmacy~what problems might occur when the current 1115 waiver is amended? Will the long-term care money disappear in the 1115 waiver?
- There is fragmentation in the current system. Fragmentation will not change
- Could we create a different ERC (Enhanced Residential Care Waiver) rate for Chittenden County?
- Coverage for vision services. Look at services that have been cut and determine what is necessary to keep individuals living independently.
- Obesity in Vermont should be addressed. Many health ramifications. When there is poor dental care, people tend to eat less healthy but easy to chew foods, e.g. mashed potatoes and gravy is easier to eat. Better dental care would help avoid obesity
- Provide monetary incentives to encourage weight loss

Franklin Grand Isle Counties Advocates for Long Term Care

June 11, 2002

Managing a Long-Term care System with a combined budget

- Scary approach because case managers will ensure everyone will get their entitlement in the community – won't this bankrupt the system?
- Home and Community Based Waiver (HCBW) does good but too little too late~easier in the past when you grow the services over time with the family~did not burn the family out prioritization has created this problem
- Waiver is not effective as a crisis intervention program~Does not move fast enough.need more flexible system that will respond will permanent system in place

Proposed Services to include in system

- No comments

Additional Support needed for LTC System

- Adequacy of current case management system, is it adequate to do case management & assessment in an expanded system?
- Not enough caregivers do private services

Eligibility

- No comments

Reimbursement for Services

- No comments

Concerns

- Why should we come up with new programs when we don't currently pay for the ones we have? (Medicaid doesn't pay adequately.)
- With current budget cuts we cannot implement new programs
- Economic climate not the right time to do something like this~need to shore up existing programs
- More services are not always better. Expanding services may not be able to stay within the budget..focus more on what we have and know
- Medicaid Waiver program is good in theory, but does not work. Use the money on home and community based waiver to make the services work the way they are suppose to.

- Home and Community Based Waiver clients are cycling back to nursing home. The acuity level of nursing home admits has increased.
- Area of concern – Are individuals being discharged because they do not meet the level of care? Would they be discharged? People in distress about leaving the nursing home.
- Make sure you learn from what other State's are doing with their 1115 Waivers
- Do we have statistics from the State on the Medicaid Waiver program, i.e. how long individuals have been on the Waiver, when they go to acute care? What services are they using?
- Can DA&D provide profiles of people by county?

Bennington Community Based Coalition

June 19,

2002

Managing a Long-term care system with a combined budget

- Need flexibility to react to individual needs
- Expand companion services and expand Adult Day services, expand Traumatic Brain Injury Waiver by providing more slots for individuals with long-term care needs
- Provide more funding for Waiver administration such as paying people to attend Waiver meetings
- Oversight is needed for Waiver Consumer Directed and Surrogate Directed cases (CD/SD)

Proposed Services to include in system

- No comments

Additional Support needed for LTC Systems

- Education for care providers about various options e.g. what about “try-out days” at adult day ~include as part of a nursing home transition package.
- Dementia needs~not nursing home/physical care needs, but supervision and cueing.
- Formalize training for caregivers. Training needed for PCA's (personal care attendants) & informal caregivers. Caregiver needs livable wages and benefits
- Individualize services, help the helpers accept services, intervene with elders sooner

Eligibility

- No comments

Reimbursement for Services

- No comments

Concerns

- Local administration of waiver is time intensive
- How can we bring acute care in, particularly around end of life care and use money saved from there? (Access Medicare dollars)

Rutland Area Long Term Care Coalition**June 20,****2002****Managing a Long-term care system with a combined budget**

- CD/SD (Consumer/Surrogate Directed Waiver clients)~some can't manage on their own. They need a surrogate agency
- Change prioritization so more people qualify for services.
- Make sure there is statewide standardization. Eligibility should be the same across the state
- Should be mandatory to have face to face home visit every 30 days, can catch more problems before they become too large
- Address mental health needs for people under age 60 who are nursing home

Proposed services to include in System

- Expand Care Partners program (AAA case managers working with physician offices)
- Fund Preventive Services

Additional Support needed for LTC System

- No comments

Eligibility

- No comments

Reimbursement for Services

- No Comments

Concerns

- Won't the total available funds in a global long-term care budget be reduced if the State loses more nursing home beds and the State receives less money from the nursing home bed tax?
- Expand Adult Day services

Connecticut Valley Health and Human Services Network

June 24, 2002

Managing a Long-Term care system with a combined budget

- If we co mingle funds through a global long-term care budget, why don't we co mingle services so nursing homes can provide other types of services?

Proposed Services to include in System

- No comments

Additional Support needed for LTC System

- Where will the caregivers come from to take care of more people at home?
- Ombudsmen program should be out in the community – not currently available
- Legal nurse services are needed~no attorneys that work in this field~Disability Law Project too limited
- Cannot provide an extra service while in a nursing home, does not fit the system~i.e. may want more cognitive services while in the nursing home but can't get them
- Expand TBI Waiver. It is too limited~need to be able to live in the least restrictive setting, but not enough slots or trained caregivers

Eligibility

- Younger disabled left out due to budgeting and planning. Current system doesn't work for the physically disabled. Cannot hire case managers for younger disabled

Reimbursement for Services

- Currently there is no way to pay through cost share/sliding fees

Concerns

- The State should fully fund nursing homes before it develops more programs
- Is there intent to close nursing home beds?
- Need to address the fact that senior centers are not recognized as part of the long-term care system

Connecticut Valley Health and Human Services Network

June 25, 2002

Springfield

Managing a Long-Term Care System with a combined budget

- If there was a cap and individuals did not use all of the money would it go back into the pot?
- Will it be managed locally?
- Family members need to be in on the budgetary planning when making decisions
- On the local level if they are determining services, they can no longer blame the State
- Transportation should be addressed. Bring those funds into the long-term care budget. There will not be the same impact if it stays in the other part of the Medicaid budget
- If aggregate budgeting what do you do when you run out? Are admissions and services frozen?

Proposed services to include in System

- Will this take into account individuals that need 24 hour care? Could the money provide companion stand by service?
- Need to allow for a type of swing bed from residential care to nursing home back to residential care
- Prevention would begin by identifying certain service that would prevent people needing a higher level of care: Examples: managing medication, prepare meals for individuals to take..Home Care needs homemaker or assistance, theses people do not need skilled nursing but if they got the services they would not need higher level of care
- .Case Management purchase of services will need to pay for the average is 4 hours a month some individuals need a lot more. The State should require a certain amount of case management time.

Additional Support needed for LTC System

- Facilities having trouble finding staff? How are you going to find staff for new programs?
- Needs to be a good source of information about where you can receive services. Need more information about providers available to consumer

Eligibility

- Do paperwork ahead of time to determine eligibility for long-term care. Should work like Section 8 housing. The eligibility should be with the person

Reimbursement for Services

- Would the State use a tiered reimbursement system in Assisted Living to pay for higher care needs (case mix system)?
- Allow for family payment without losing benefits
- Should have a sliding fee

Concerns

- Will caregivers be licensed nurses aides?
- There is a cost to the system of security checks on caregivers
- How do you maintain the budget neutrality?

Windham County Long Term Care Network June 27th, 2002**Managing a Long Term care System with a combined budget**

- How will the State ensure the quality of home and community-based services in an expanded system?
- “Underground” care system is rampant. These people give questionable care and do not pay taxes. No assurance of quality. People hire underground network to provide care if Medicaid does not pay for enough care
- Have anyone who is in a caregiver role demonstrate they have adequate training
- What process will be used to make the decision? Will they be made on the funding allocation or managing the money?
- How will we track the quality of care at home? Not equal to the quality assurances that currently exists with nursing homes.
- Under a more flexible system could part of a nursing home be used for other services for seniors living at home? Would help keep nursing homes available. Beds could be available in the future if needed.
- Quality of care by caregivers hired by the family suggest short intensive training program for the caregiver & build in tracking system so the State can track system to have on going information.

Proposed services to include in System

- Housing and room & board costs ~ most people who have been in nursing homes for a while have given up their homes. In this area the vacancy rate is less than 1%. We could not find homes for people to go to.

Additional Support needed for LTC system

- Where will there be the money to pay caregivers & staff to provide the services? Not enough trained people~not enough people willing to work for the wages, this is a problem not enough people
- Need more care providers in a rural area, than an urban area
- Need for more training of surrogate & self directed care
- Residential care plays an important role~need to recognize
- Cognitive impairments are difficult to evaluate~they need special attention during assessments. Special attention needs to be paid to the self-neglecting elders. Should not be overlooked as a normal part of aging

Eligibility

- No comments

Reimbursement for Services

- No comments

Concerns

- Not an efficient use of caregivers to provide care by expanding home care. It's more efficient and effective to serve people in a congregate-type setting
- Isn't it a conflict of interest for Home health to assess individuals who are potential clients? (Comment about current Waiver system.)
- Two hours of care in nursing home is not equivalent to two hours of care in a private home. Nursing home care can spread the care over a day
- Will nursing homes continue to be available? Will there be greater flexibility for nursing homes so they can better manage the numbers?
- Will people always have money to access to care?
- Could we get a Waiver to bring in additional providers?
- Percentage of population with Alzheimer's disease is increasing.

Additional comments

“I am a Benefit Programs Specialist at PATH and am one of two workers in our office who work with Long Term Care Medicaid eligibility. You mentioned exploring whether earlier intervention with Medicaid waiver services, say at Level III or IV could prevent or postpone nursing home admissions. I would like to see this happen, but you might then need to ease the financial requirements, perhaps by allowing spouses at Level 3 or 4 to separate their finances. For single or widows individuals, perhaps allow the LTC Community Maintenance standard rather than the Community Medicaid income maximum, which is lower. I would also like to see the disability determination process for younger adults streamlined. At the present the Medicaid disability decisions are handled by the same people who process social security disability decisions, a process that can take up to 3 months. If a person is at Level 2 or Level 1 with a condition that is terminal and/ or expected to last a year or more, could e not handle those cases in house and streamline the process for the person under age 65 and older than 20? If not in house, could these cases be earmarked in some manner for a really fast track with DDS. The waiver services that these people receive prior to the disability decision are paid retroactively after the Medicaid is granted. It is not reasonable to expect the service providers to wait several months before anyone is paid, and puts a real hardship on the disabled person waiting for full medical care. I also find that I must sometimes delay a Medicaid waiver approval due to delays in plan of care approval from DA&D. Another gap in services is for the younger person who, (for example non-terminal treatable cancer, or sudden traumatic injury) is incapacitated at Level 1 but is expected to recover in less than a year. This person is denied Medicaid. If the person has VHAP, intermediate care services are covered for only 30 days, the patient can't get Medicaid at all if expected to recover within a year but may need skilled nursing services for more than 30 days. Another thing that I would like to see is for the elderly and the younger disabled people who are over income for Medicaid to be able to pay the monthly amount of the spend down as a premium and in effect purchase their Medicaid coverage. Many of these folks have Medicare only or for the newly disabled, no coverage at all for the first two years. This leads to an avoidance of all but emergency and

critical care. Preventive care is non-existent for these people and in some cases could lead to nursing home admissions later on.

“I was alarmed at the last WCLTCN general meeting to see/hear that the Eden Park census is dangerously low, as pointed out by Eden Park’s administrator. It is close to the number, which makes the state close nursing homes. (I personally see an important role for nursing homes although there are those in the administration and also in Brattleboro who want to shrink them even more). As you’ll see from the minutes, we were talking about the huge problem of inadequate trained staffing personnel in the community to provide for high quality, or even any quality home care needs, even if more money is there to pay the puny salaries. If home care is to be expanded thus with the waiver, and if nursing homes shrink even more, with sicker people at home, what kind of care can we expect? With the severe nursing shortage facing acute care hospitals today, the patients will either not get admitted or have to leave sooner than ever, and back home to what?

Is that “healthy aging”? Is this what “aging in place” at home has come to mean? The families are already providing over 50% of home care in the US (National statistic), and family members often have inadequate skills for the care needs, on top of the stress/burnout factor.”

The need for much better oversight of the patients/clients at home is a corollary of the concern.

Another important point, mentioned at the last meeting, is the lack of data on numbers and levels of disability and need for help of homebound seniors. What is the state doing to get the data, and how can the state track outcomes/results without accurate data? In the field of medicine, including geriatrics and long term care, there is a lot of discussion about the need for information on outcomes of treatments, medical care, procedures, etc. It is very difficult to get accurate information.

If the state lacks data, we can’t even know the simplest outcome measurement:

- 1) Is a need person getting care or not, not to mention
- 2) Is it good quality or not, and
- 3) Is the patient benefiting from it?

How are the concerns expressed at this open meeting going to get incorporated into the planning process and what form of feedback will be provided to us as participants in the process?

As I was reading the Burlington Free Press this morning I saw the article about Long Term care and you're upcoming seminar in Burlington...I probably will not attend but I have an idea. Explore the possibility for the State of Vermont to contract with an insurance company for Long Term Care coverage for some of the states more "at risk" Medicaid clients? I took one out through Bankers Life when I was 60, so age would not be prohibitive premium wise...the premiums are \$42.00 per month and can never increase. I will pay for IN HOME care for 364 days at \$100.00 per day. Not a lot but it could keep me out of a nursing home for a year. It seems that this might be something worth exploring. For around \$500 per year per potential client coverage for a year would be guaranteed.